"What's up, Doc?"

Malcolm MacCulloch

"When you're back in Toronto," said my wife, "will you see if you can get me some more of those lovely hand painted T shirts?"

The busy week had gone well and I had half a day to kill before the evening flight home. Then I remembered the shopping. I set off down to the water front, and as I walked I noticed a sensation in the chest—it wasn't a pain at all and didn't change. It couldn't be my heart; to prove it I walked for hours. I was no worse, but I didn't find the T shirts.

I was breathless when I got home next day and concerned. My blood pressure was 170/110 mm Hg, so that was it. My general practitioner confirmed the raised blood pressure and I saw a physician, who made a diagnosis of "stress" but just to be sure arranged for exercise cardiography. All the other tests were "normal" but at six and a half minutes, long after my symptoms had been reproduced on the treadmill, the attending registrar announced that I had definite ischaemic changes in the electrocardiogram.

My son Tom, a medical senior house officer, explained that no one could know what was happening in the coronary arteries unless they were seen. Thus fortified with new knowledge I went to see the physician to discuss the electrocardiogram. "You've got very mild angina, I'll prescribe some tablets. You should remain off work and go for progressive walks." I felt ill, I was breathless, and couldn't go far without a physical feeling of unease. To be thus dismissed was unsettling. I suggested referral to a cardiologist. "Absolutely bad medicine, it's mild and not getting worse." I revealed the source of my new cardiological knowledge, but referral to a cardiologist was angrily refused. By the end of the next evening Tom had rung back with the name of a cardiologist, and he repeatedly reassured me that angiography was a must. I felt unwell, upset, and confused by the conflicting advice I had had.

The cardiologist was away on leave, so I settled down to wait. Soon I had clear exercise limitations and the strange chest sensations continued. I seemed to be getting worse. The cardiac consultation was crisp. The history that seemed vague to me was assessed as definite for a myocardial infarction. Electrocardiography confirmed an infarct, and my heavily loaded family history was elicited in detail. "You must have a catheterisation—I think you will have several lesions." Of course, I had been primed by Tom. "What's the risk of a catheterisation?" "One in 5000, but then you've just survived a 1 in 20 mortality risk with the coronary thrombosis you had in May." The die was cast; we took the family on holiday, and I was supported by the addition of a β blocker and a sublingual spray. "Whatever you do don't reproduce the sensations, use the spray." My wife did all the driving for the first time ever and I sneaked shots of sublingual spray when the going got too steep up the main street of Aberfeldy.

. . . who is going to persuade clinicians to refer all patients with cardiac pain?

I arrived at 8 am for an overnight stay chauffeured by my grimly cheerful wife, who drove home alone carrying my clothes. I accepted a shot of intravenous diazepam, so that the puncture of my right femoral artery seemed just a firm push. A theatre tape deck was started—I think it played the waltz from the space odyssey film *2001*. I suggested some Wagner but drew only good natured sniggers. "Cough." There it was on an illuminated screen to my left, swaying like a lamprey in a fast current. The first catheter and then momentary black tentacles like a baby squid writhing, but I saw a square gap at the base of one of the tentacles. Nobody spoke. Rummage, a sensation at the groin, the second catheter in, I thought. "Cough." The second lamprey. It looked the same but I figured it must have a different shape. Then another damaged tentacle. Again no one spoke. I was given some sublingual spray for my chest sensation. Soon I was rumbling back to the ward, lying down this time, but quite elated that I had faced and actually been fascinated by this now commonplace complex physiological procedure.

The right artery was 99% blocked and there were multiple blocks in the left of between 60 and 80%. "Before you speak to the surgeon," I said, "would you have the operation here?" "Without hesitation, they've got the figures." "What are they?" "Eight per 1000"—mortality. It seemed a good swap for the 1 in 20 I'd already survived and I didn't like the look of that 99% block on the right. I felt trapped by my illness and I spent the long evening in deep thought.

The surgeon appeared in theatre garb at 8 30 am the next morning. He explained that the bypass operation wasn't mandatory. For a moment I was confused, then I suddenly realised that the surgeon was being fair. "It's your decision," he said twice. I reverted to psychiatric tricks. "Let's assume I'm the surgeon and you are the patient," I said, "what would you do?" "Oh, have the operation." The decision made, an army of staff gradually and subtly descended on me.

First of all the sister—it came out in conversation that she had had a successful bypass operation several years before. I brightened. The physiotherapist taught me how to breathe, cough, and move with a painful sternum. A young and pretty nurse specialist from the recovery unit lucidly explained the complex postoperative procedures, and as the days went by more electrocardiograms and *x* ray examinations were done. The anaesthetist came by one evening at 7 pm, followed by a research senior registrar—could he measure my chest impedance to develop a measure of fluid retention during operation? "Of course." Finally, the Hibiscrub baths and the whole body shave. That took two hours—we are all related to Esau. I didn't know what to say to my wife. In the end I said, "I'll see you in two days' time," and I decided not to write last letters to my four children, although I did wonder.

The cardiac recovery suite seemed all bright white and I remember snatches of that 24 hours. My nurse was a solid immensely reassuring Welshman, who softly explained everything before it was done. The tracheal tube was easy. A murmur, "I'm going to give you something to get rid of the excess fluid in your chest." A shot of diuretic into one of my intravenous lines produced a flush of warmth in my lower abdomen and in the indwelling urinary catheter. I realised immediately that my breathing was easier; a veritable merlin. Two nurses sat me up to take out my drains, both like terracotta daggers, one from the lower chest and one from the pericardium. I thankfully watched nurse number two pull and tie the purse string sutures. Then, with just one intravenous line and the crackling oxygen mask and a monitor, we trundled, with me semiconscious, through to the adjacent cardiac surgery ward.

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No one had told us of the hallucinogenic effect of dihydrocodeine. I woke with a start to sinister cackling and was observed by an eye which I knew belonged to a boy from school. The next night there were children ranged round the ward and King Neptune stood in the entrance to the dispensary. During the course of one night a nurse's shoes turned to illuminated wings. Over those first 36 postoperative hours I began to hate the ward at night, as I lay watching my newly operated companions unconscious, with their features obscured by a spray of water vapour from the insistently crackling oxygen lines. It seemed I was in a Dantesque oubliette into which I and my fellows had been lowered in order to enact some horrible scene from the film *Alien*. These night time

horrors all changed after we stopped taking the dihydrocodeine and reverted to simple paracetamol, and the daily shower administered by the auxiliary nurses soothed away the sense of alienation. We were sluiced in warm Hibiscrub solution, showered down, patted dry, and swaddled in heavenly heated sheets.

As I gave my discharge history to my surgeon a line from Psalm 103 came to my mind:

> He satisfies my desires with good things
> so that my youth is renewed like the eagles

The sword of Damocles had been moved to one side and each day had become a precious symptom free bonus.

It had all been so sudden, just a few weeks of disability and then an urgent coronary bypass operation, not 20 years of medical management of angina. The immense psychological impact of thoracotomy fills the mind for months, as does gratitude for the relief of a demeaning impairment. One of my nine inpatient companions had initially been told that his coronary was healing and that that was all there was to it. His forceful nature led him to a cardiologist and he had a six vessel bypass operation the week before I had my operation. Another patient had been diagnosed as suffering from cervical arthritis before the true nature of his intensely variable symptoms was appreciated. So out of just 10 patients whom I know personally I was not alone in being the potential victim of diagnostic uncertainty.

There is just a whiff of clinical audit in the air; but it's a very delicate matter. A recent paper by Dr L Quam which presented an alternative to *Working for Patients*, suggested that we should improve clinical practice by "monitoring the introduction and standardisation of diagnostic methods and treatment modalities based on the results of clinical trials . . . and by detecting severely substandard performance by a doctor or a hospital through the monitoring of clusters of adverse events."

But who is going to persuade clinicians to refer all patients with cardiac pain? Who is going to do something about the tenfold disparities in risk between neighbouring cardiac surgery centres? And who is going to make it possible for centres such as mine to operate on the 200 other patients a year who suffer a lethal attrition on the waiting list? I used to have a dim perception of these problems but now they are real: NHS reform on the basis of clinical effectiveness is the only way to go.

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MEDICINE AND THE MEDIA

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The scandal of Leros

"However many riches you may acquire in life, death comes to us all," sings an old woman, one of the 1100 abandoned patients incarcerated on the Greek island of Leros. Hospital guards too express the feelings of hopeless resignation that inmates experience: "They'll never go home or get better," and treat their charges as subhuman, believing, "They're dumb animals, they've no feelings." For some time among European mental health professionals the scandal of Leros has been an open secret. In 1983 the Greek government, acknowledging the violation of human dignity in the hospital, sought expert help and advice from the European Community, and the following year a joint Greek and international team of psychiatrists went to Leros. They recommended a five year plan to implement closure of the hospital and the input of two million pounds from the European Social Fund for this purpose.

A television team visited Leros last year to see what progress had been made. "Island of Outcasts" presented the grim reality of life in the asylum now. In the notorious Pavilion of the Naked men are still left to wander around the compound without clothes; unlucky ones are chained. There is no treatment or recreation, nothing to relieve the awful daily monotony.

The colony of mentally ill on Leros had more auspicious beginnings, founded 25 years ago by royal decree to ease overcrowding in hospitals on the mainland. In the early years massive transportations of human cargo took place. "Island of Outcasts" reported that some people were committed there because they had received treatment for

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tuberculosis, were petty thieves, or had fallen out with their families. Many of the patients now do not seem to know why they are in the asylum. The sole psychiatrist responsible for the male inmates was seen interviewing one of his charges; he commented, "At one time patients had symptoms of psychosis, but their symptoms now are not their original ones but the symptoms of institutionalisation."

Although almost a third of the patients would like to move, discharge from Leros is rare. In order for it to happen a member of the patient's family must sign a release form agreeing to take on responsibility. "Island of Outcasts" followed up the case of a 27 year old man with slight mental handicap who had been in hospital for 10 years. His dream was to go home. At the long awaited meeting between this man and his family his sister was too distressed to talk to him, while his mother dreaded discussing his future plans, explaining, "I would sign [the form] but the child is a bit retarded." When the young man's two hour pass expires he returns to his ward and his family return to their home in Athens. Another patient's mother, who lives on an island just 10 miles from Leros comments, "I loved my son so much, I haven't the heart to go and see him. What should I do? The doctors said he should be in hospital."

Patients who do leave often face enormous problems. Katina, admitted over 20 years ago, slowly "came back to life," and in 1983 she was discharged and went to live in her own home, but she soon returned to the home she knew better—the ward. With no rehabilitation facilities to prepare patients for discharge it is not surprising that people fail to cope with life outside. The institution raises psychological as well as practical issues. By the process of "islandisation" people are physically isolated, while psychologically the insane can be contained within a compartment or island in the human psyche. Successful "de-islandisation" will demand greater acceptance of deviant human behaviour.

Last summer a small group of Greek, Italian, and Dutch doctors tried to get things moving. They chose 20 of the most regressed patients and by making simple changes in their living conditions achieved dramatic results. Within five days the men had learnt to go to the toilet and to locate their own beds in the dormitory and had begun to go for walks with staff. Success was shortlived, however, owing to problems in coordinating with other volunteer workers and financial difficulties, and after five months the programme of reforms was abandoned.

Delegates meeting at the eighth world psychiatric association congress in October 1989 in Athens urged the Greek government to take the initiative and use the resources made available by the European Community in 1984. Yet Greek health officials are not committed to closure of the hospital, and Greek doctors do not wish to work there. A feeling of fatality hangs over the asylum as nearly every week one more patient dies.—ROSALIND RAMSAY, *registrar in psychiatry, University College Hospital, London*